NATIONAL
ANKYLOSING
SPONDYLITIS
SOCIETY
NASS UK

Annual Review 2018

Supporting people with axial spondyloarthritis including ankylosing spondylitis

> “A massive thank you to everyone at NASS for all the magnificent work that you do. I can honestly say that being able to contact you just by picking up the phone gives me great peace of mind.”
>
> David, NASS Member

Message from the Chair and Chief Executive

200,000 people in the UK have AS, the average age of onset is 24 and the current average delay to diagnosis is 8.5 years


Raj Mahapatra


Dr Dale Webb

Welcome to the NASS 2018 Annual Review. As the only UK charity dedicated to supporting people with axial SpA (AS), each year we renew our commitment to supporting the 200,000 people in the UK who live with axial SpA (AS) along with their friends and families.

All too often people with axial SpA (AS) tell us that they have had to wait 10 years or more for a diagnosis, so the publication in 2018 of an NHS Quality Standard for Spondyloarthritis was a welcome development. It sets out priority areas for quality improvement for NHS commissioners and providers. However, the Quality Standard by itself will not be enough to ensure that high quality care is provided right across the country because there are no incentives for implementing it nor penalties for failing to do so.

That's why, in the autumn, we launched our Every Patient, Every Time campaign at an event in the House of Commons. We want every patient, every time to receive timely diagnosis and effective care.

We need effective national oversight of the implementation of the Quality Standard. In December we announced the formation of the first ever parliamentary committee on axial SpA (AS). The All Party Parliamentary Group will commission analysis and publish reports on the quality of axial SpA (AS) care, and identify examples of excellent care as well as areas where care needs to improve.

We also need to support clinicians who are working hard to create service improvements. Our new Aspiring to Excellence programme will recognise and nurture those outstanding patient care teams currently delivering services to people living with axial SpA (AS). We expect their shared learnings to inform our work and to improve skill sets and axial SpA (AS) service delivery across the NHS and beyond, for years to come.

We are also closely monitoring threats of closure to hydrotherapy pools around the UK—as NHS budgets are reduced, more threats to service provision are certain to arise. We know these services are essential in equipping patients to self-manage their condition, and we will never sit back when services needed by our community are underfunded and under attack.

Our Every Patient, Every Time campaign has got off to a great start. Extending our partnerships with clinicians, parliamentarians and professional bodies has helped to raise awareness of axial SpA (AS) and focus hearts and minds on reducing the time to diagnosis. We will be relentless in our focus – people with axial SpA (AS) deserve nothing less.

At the heart of our work are our members and our branches. 2018 saw the launch of our new NASS Voices community engagement events, which complement our branch network in enabling us to connect with people on a regular basis right across the UK. Whereas NASS Voices provide the tools and information to support axial SpA (AS) self-management, our 95 branches offer the opportunity to stay connected and active every week through exercise and hydrotherapy sessions, supervised by specialist physiotherapists.

We launched our new website, and have transformed NASS membership into a real partnership, with an upgraded online forum and new opportunities to contribute to the path we will take next in our work. People typically start to develop symptoms in their late teens to early 20s which is why it is so important to reach out to young people. We were delighted that our online portal for young people—ASone—was the inaugural winner of an international award for best campaign or initiative focused on young people with rheumatic disease.

Research is key to understanding axial SpA (AS) and that's why in 2018 we funded our largest ever research study. The British Axial Spondyloarthritis Inception Cohort (BAxSIC) study will monitor thousands of patients over time, to evaluate the impact of delay in diagnosis on people's health and lives to help improve care in the future.

We want people with axial SpA (AS) to know that we are there for them whenever they need support. Our confidential Helpline offers personalised up to date information and support five days a week. A full complement of patient guides and other self-management tools can be accessed at any time on our website and our vibrant forum and social media communities present opportunities to connect with others and share ideas, observations, and concerns around the clock.

NASS is growing so that we are better equipped to take on these challenges, but we couldn't do it without our supporters. As a charity we receive no government funding, so we offer our deepest gratitude to all those who have supported our projects throughout NASS' 42 year history: from our wonderful members, to our extraordinary fundraisers; from those who so generously leave a gift to us in their wills to all the loved ones who stand with us as we fight to secure better futures for everyone in the UK living with axial SpA (AS).

NASS is proud to have the distinction of being the first charity in the world set up to provide information and support to people living with axial SpA (AS). We are proud to advocate on behalf of patients and we were determined to ensure that Every Patient, Every Time gets early diagnosis and effective care. Thank you so much for your support.

Raj Mahapatra, Chair

Dr Dale Webb, Chief Executive

> **“NASS is a great source of information for people living with AS and champion many valuable (and essential) projects. It is great to be a part of this.”**
>
> Feedback from a NASS Member

Goal One:

Reducing the delay to diagnosing axial SpA (AS)

No-one should have to wait 8½ years for a diagnosis of axial SpA (AS) - living in pain, uncertainty and anxiety, without the vital treatment and care that can transform lives. To reduce the time to diagnosis and ensure effective care to patients, it’s essential that we improve clinical familiarity with axial SpA (AS) and find ways to ensure that healthcare commissioners and providers implement the NICE guidelines and Quality Standard in full. We campaign with vigour, and we educate with the vision that we can and will reduce that delay.

In the autumn of 2018 we launched our *Every Patient, Every Time* campaign to ensure widespread and effective implementation of the Quality Standard for spondyloarthritis, so that every patient, every time gets early diagnosis and high quality care.

A key pillar of this campaign is our work with MPs to form a new All Party Parliamentary Group (APPG) for Axial Spondyloarthritis. The APPG will run for two years, conducting and reviewing freedom of information requests (FOI) to commissioners, reviewing data from the Early Inflammatory Arthritis Audit and other relevant research, and publishing reports.

Work also began in 2018 on our new *Aspiring to Excellence* programme, set to launch in spring 2019. This clinical award programme is designed to encourage and recognise service improvement in axial SpA (AS) care. The knowledge and experience generated will be shared in real-time across the UK and internationally to help stimulate across-the-board improvements in care.

The programme is a strategic partnership between NASS, the British Society for Spondyloarthritis (BRITSpA) and sponsoring companies AbbVie, Novartis and UCB.

NASS continued to develop our partnership with the Royal College of Chiropractors and Institute of Osteopathy, delivering training seminars and creating a new, easy to use referral template.

A survey of 382 practitioners conducted in summer 2018 identified difficulties clinicians have faced when recommending onward referral in suspected cases of axial SpA (AS). This learning led to the development of a template for osteopaths and chiropractors to use when writing their recommendations to GPs. We are delighted that this tool has now been endorsed by the Royal College of GPs and Chartered Society for Physiotherapy.

We’re looking forward to launching the referral template tool and moving forward with continued delivery of the NASS Allies seminar programme throughout 2019.

We’re fighting to reduce the **8.5 year** average delay to diagnosis in the UK

Over 100 Osteopaths & Chiropractors attended NASS Allies pilot events

We created the **first ever parliamentary committee on axial SpA**

NASS UK EVERY PATIENT EVERY TIME

> “It’s crucial that the NICE Quality Standard is implemented fully across the country so that no-one has to live in pain without treatment and support.” — **APPG Chair, Derek Thomas, MP**

Goal Two:

Ensuring that people with axial SpA (AS) have the support they need

When you are living with axial SpA (AS), a single annual rheumatology appointment can seem a lifetime away. Where can you turn for advice in flare? What should you expect from your care team? What is the latest research? Where can you find other people with axial SpA (AS) to talk to? Throughout the year, you'll find NASS right here.

Since our beginning in 1976, the provision of information and support has been an essential part of the work we do, and 2018 was no different. Over the year we responded to 5,570 calls, emails and Facebook messages seeking advice, information and support. As part of this we assisted around 100 people with axial SpA (AS) with their PIP applications and appeals (worth an average of £3779 per person per year).

Our 16,600 Facebook followers raised many engaging questions, shared experiences and debate which has informed the projects we completed throughout 2018 as well as those to come. Topics such as mental health, exercise, medication concerns, and managing flares and fatigue came to the fore regularly and were a firm focus for our attention.

We launched a brand new website in October 2018, serving up a combination of the latest news, information, and research to more than a quarter of a million visitors. The improved user experience and functionality of our new website were well received. Our new member forum has been buzzing from day one, with an average of four new topics a week.

More than 40,000 of our guides to living with axial SpA (AS) were delivered directly to hospitals and axial SpA (AS) clinics Including our main guidebook and our guides to flares, work, biologic therapy, fatigue, uveitis and driving.

We worked with funding partner Novartis on two key projects. To support implementation of the NICE Spondyloarthritis Guideline we developed the 'Your AS Journey' online tool, which was launched on World AS Day. It is designed to help people understand the guideline and the care they should receive. It includes videos of both healthcare professionals and people living with axial SpA (AS). We also helped develop Novartis' Shape Your AS Future campaign which supports people in working with their rheumatologist to identify their needs and build a personalised care plan.

In 2018 the biologic drug Humira (adalimumab) lost its patent, which allowed biosimilar versions of adalimumab to enter the market. Throughout the year we worked with NHS England, along with other patient groups, inputting into the process in an attempt to ensure all relevant patient information would be available. We will continue to monitor any changes throughout the coming year and to provide guidance and input to the relevant clinical bodies.

The ASone community for younger people is growing as well, with 8,000 unique visitors to our ASone website (up 150% from last year), 21 new blogs from contributors and 8% Instagram engagement over the year (well above the average of 3%).

> I know that I am stating the obvious when I say that NASS is a great organisation; helping its members in lots of ways to deal with AS health related issues. — **Ian, NASS Member**

8,000

unique visitors to our ASone website (up 150%) with 21 new blogs and 8% Instagram engagement

In 2018 we supported **almost 100 people with axial SpA (AS) with their PIP** reviews and applications **(worth an average of £3779 per person per year)**

61,000

views of our YouTube information videos

and followers increased by 52%

92% of our members joined NASS to receive information and support and **91% are likely or very likely** to recommend others join

Goal Three:

Empowering patients to self-manage their condition

We want to ensure that people in the UK living with axial SpA (AS) have access to the tools and resources they need to self-manage their condition. We do this using a combination of resources available online and in hospitals as well as providing face to face opportunities to learn and connect with others.

Exercise is the most important thing anyone with axial SpA (AS) can do to manage their condition, a message that NASS shares on a daily basis. NASS branches provide weekly or fortnightly physiotherapy and /or hydrotherapy sessions which are supervised by a fully qualified physiotherapist with a special interest in axial SpA (AS). Our 95 branches are run by nearly 300 dedicated volunteers who give a huge commitment to the charity and are the cornerstone of our community outreach.

We worked with AbbVie to create a case study video of our Stockport branch, now with over 800 views on YouTube. The video looks at how our branches are an essential means of supporting people with axial SpA (AS) in ensuring they undertake regular exercise to maintain optimal health. A new series of exercise videos is currently in the early stages of production, due to be released in late 2019.

Our latest successful Members Day was held in June with 180 attendees. In September we launched our NASS Voices community engagement events in Stirling, Scotland and Belfast, Northern Ireland, featuring practical talks and activities delivered by rheumatologists, physiotherapists, branch representatives and members of the NASS team. Nearly 80 delegates attended between the two events. Our programme continues throughout 2019 in Cardiff, Southampton, Leeds and London.

> Here at NASS Salisbury, we have a great social life as well as a great exercise class session in our hydro pool. Every week after our Tuesday sessions about 8 of our class go to different restaurants in the city for a meal and drinks to relax and discuss their ailments! Twice a year—one in Summer and one at Christmas—we have a great party where all members of our team are invited to attend with partners, and all our physios; always great sessions! For the last couple of years 5 or 6 members go away to Spain in November, to chill and relax for a long weekend! It's great to have a fantastic branch, with great physios.
>
> **— Nigel, NASS Salisbury**

> The local branch was invaluable when I was first diagnosed and continues to provide me with the right exercise opportunity. The information on the website is clear and accurate. It does not scaremonger, but is supportive and positive. **— NASS member**

100 **axial SpA clinics and hospitals now listed in Services Near You**

180

people attended our Members Day

This annual event brings our community together to learn and connect

£1.3 million

savings to the NHS

via 559 hours of physio undertaken by 800 attendees of our 95 branches

Goal Four:

Raising awareness of axial SpA (AS)

There will be no road to an earlier diagnosis unless you know what you're looking for. Still, although 1 in 200 adults in the UK have axial SpA (AS), awareness remains too low, and an 8.5 year delay to diagnosis holds fast. NASS works every day towards changing this by taking action to raise awareness amongst clinicians, professional bodies and the general public.

We know that axial SpA (AS) is not a rare condition. But until many more voices join us and become loud enough to be heard, the threat of invisibility remains. So we take to a multitude of social media channels daily to reinforce our messages, reminding people of what symptoms to look for, and what to do if they have concerns. We ask our stakeholders to share content and engage people who aren't already aware of axial SpA (AS). We will press even harder in the coming year.

NASS regularly re-circulates essential and popular information such as our Back Pain+ campaign—a tool which points out what other conditions may be indicating underlying axial SpA (AS) to support clinicians in fields like ophthalmology, dermatology and gastroenterology in providing timely patient referrals.

We regularly partner with professional bodies to collaborate with other organisations facing similar issues and to help expand our reach. We are looking forward to growing these relationships and embedding new ones during 2019.

> Having had ankylosing spondylitis symptoms since I was 21 years old, I felt that the medical profession didn't have the capacity to recognize the symptoms and effects of what has been around for 2,000 years.
>
> **Stephen**

We're reaching out to raise awareness…

Facebook reach across all channels:

1,567,000

Followers: 17,110

Twitter reach across all channels:

1,964,000

Followers: 10,600

YouTube Followers:

1,245 (growth of +650)

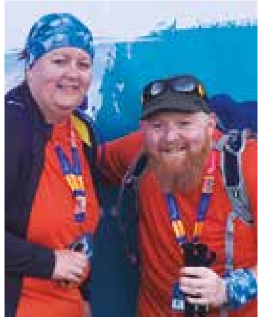
Video views: 61,000

Instagram followers:

1100

Engagement 8%

Today's generosity shapes tomorrow's changes. Thank you, supporters!



NASS Member Gareth and his wife Naomi Dwyer tackled the 25km Wye Valley Challenge in 2018, raising awareness of axial SpA (AS) and support others living with the condition. The event was a very personal one for the pair, as Gareth was diagnosed with axial SpA (AS) after he fractured a vertebrae in the lumbar part of his spine.

Gareth said:

"It's possible that I've had the condition from my late teens, but an active career and being a keen rugby player might have prevented it showing its symptoms. After diagnosis I researched for support and found NASS. I enjoy your Members Day every year with expert speakers, exercise advice and the chance to meet others with AS so we can support each other. NASS has helped with providing support not only for me but Naomi as well. I completed this challenge as a thank you for the help NASS has given myself and Naomi."

Naomi said:

"The first 11k was gruelling, very hilly but with some amazing views of the landscape. Gareth did really, really well. We supported each other on sections of the route we struggled with and that's how we got through it! AS is a cruel condition that effects both physical and mental health. NASS has given me the tools to support Gareth's AS and his flare ups and can't thank you enough."

Gareth and Naomi have raised over £1,000 for NASS - enough to fund 500 calls to our helpline from people in need. Thank you both for your incredible support!

We received a generous

£539,136

in legacies

With gratitude, as we look ahead to improve lives in the long term.

Our membership is growing - at the end of 2018 we had

3,412 members.

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95 fundraisers raised

£62,004

for us in 2018

We are so grateful for everything you do to support us!

Help NASS shape brighter futures for generations to come

NASS is proud to partner with the National Free Wills Network, giving supporters and Members the opportunity to meet with a local solicitor and have a simple Will made or updated for free.

There is no obligation to leave a gift in your Will to NASS, but we really hope you choose to do so. Every gift, no matter the size, will help us to continue our work and transform the future for people affected by AS.

Leading the way

The voice of NASS is really the collective voice of our members in unison with the voice of our leadership. We all work together to secure positive outcomes. Throughout 2018, you spoke and we listened; on everything from membership to your views on cannabis. We look forward to working even more with you in 2019.

Our Council of Management is comprised of people with axial SpA (AS) as well as active and retired clinicians. The combination of expertise and life experience ensures that we understand all of our stakeholders equally and our decision making is sound and sensible. Who better to take key decisions affecting the axial SpA (AS) community than people living with the condition, in close collaboration with the country's top experts in axial SpA (AS)?

To ensure that NASS is able to achieve our ambitious long-term goals trustees approved a growth plan from our new CEO. We have created new roles to ensure that we deliver significantly greater public awareness of axial SpA (AS), new events to reach out to people living with the condition, new programmes to influence policy makers and clinicians, and new approaches to strengthen our income base.

This is the leadership which will continue to take NASS into our next phase of growth. We remain stronger together.

Our Medical Advisory Board has a combined **300 years' experience**

NASS is fortunate to have some of the UK's leading axial SpA (AS) rheumatologists, physiotherapists and nurses work with us on a regular basis. They provide outstanding clinical advice, helping to ensure that our information is accurate, reflects the latest clinical evidence and that we engage clinicians in ways that will be most effective.

1640 Members sharing their thoughts in 6 2018 surveys

Participating in regular formal and informal research offers members opportunities to contribute to our charity's direction

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Of our 18 Trustees, 14 are people living with axial SpA (AS) and 4 are health care professionals

Leaving a lasting legacy

Gifts left in Wills (also known as legacies) have made a huge difference to NASS. In fact, last year 58% of all income was from gifts in Wills, so we really wouldn't be able to continue without them. They have helped us to improve our services, launch new projects, and fund vital research into better treatments for axial SpA (AS). Here are some examples of how our legacy funded research fund is helping to make a difference.

The Richard Horsford Award

A National Survey of the Provision and Attitudes towards Hydrotherapy

Led by Melanie Martin from Guy's & St Thomas' NHS Trust and Claire Jeffries from Solent NHS Trust, this study mapped the current provision of NHS hydrotherapy services for axial SpA (AS) across the UK and captured patients' experience of hydrotherapy. The results highlighted the benefits of hydrotherapy in managing AS, the challenges of accessing hydrotherapy due to the pool closures and the importance of continuing to deliver hydrotherapy through the NHS. Talks are also currently in progress with BRITSpA about continuing this very important piece of research and NASS will also be working to continue with the #saveourpools campaign.

The Audrey L Pape Award

Improving the assessment of fatigue in Axial Spondyloarthropathy

Led by Kirstie Haywood and Nathan Pearson at University of Warwick, this study aims to develop a patient co-constructed axial SpA (AS) fatigue specific questionnaire that is relevant to the patient experience of fatigue, with evaluative evidence of its statistical properties. The project is being conducted in three phases; a systematic review of the quality and acceptability of fatigue questionnaires used in axial SpA (AS) fatigue assessment, qualitative research with axial SpA (AS) patients, healthcare professionals and researchers and questionnaire development and refinement.

The Katherine Grace Upton Award

Assessing the impact of rehabilitative interventions on the natural history of ankylosing spondylitis

Led by Matthew Young at the University of Bath, this project begins in 2019. The project aims to determine the long term impact of rehabilitative interventions on the natural history of AS with two objectives: to prepare over 30 years of past clinical records and to conduct an initial retrospective analysis assessing the role of residential rehabilitation courses on the natural history of AS. This database will enable us to better understand AS, predict biological and social outcomes, and to determine the true benefits of treatments and interventions.

Society money

Income

Legacies	47%
Branch income	16%
Sponsorship	10%
Donations	9%
Membership	7%
Community Fundraising	6%
Other	5%

Expenditure

Education & support	57%
Campaigning	16%
Raising funds	14%
Research	8%
Governance	5%

More in depth information is available in our Trustees Report and Annual Accounts at **www.nass.co.uk**

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National Ankylosing Spondylitis Society (NASS) is a registered charity in England and Wales (272258) and Scotland (SC041347)

With thanks to our major donors and corporate partners

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E M Chossudovsky
P Livesey
B Hussey
M Dixon

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The Bernadette Charitable Trust
The Khayami Foundation
The Mary Homfray Charitable Trust
The Simon Gibson Charitable Trust

From funding vital research to providing life-changing services, leaving a gift in your will can make an enormous difference to the lives of future generations affected by AS. If you would like to know more about how you can leave a lasting legacy of support, **please call Katie on 020 8741 1515 or email katielyall@nass.co.uk.**